

3. Appendix




Sample Materials for Recruitment, Orientation, Organization, and Appreciation of a Patient- and Family-Advisor Group

Recruitment flyer and postcard

Do you have a child with special health care needs?

Would you like to help train future doctors to care for families like yours?

Join the "Family Competency Project"



Ways to participate:

Host Medical Student Home Visits
or
Attend Focus Group Discussions
or
Share Your Thoughts by Phone Or E-Mail
or
Answer Surveys

Requirements:
Be an active duty or retired military family or family member who is the parent of a child with special needs

Please call: Penny Veerhoff (xxx) _____

Jan Hanson at (xxx) _____

Thanks!

Sponsored by the Uniformed Services University of the Health Sciences

The Family Competency Project

The medical students at the Uniformed Services University learn so much from people who have experienced medical care. You share an essential perspective teaching the next generation of physicians. If you can help us again, please return this postcard, or call Jan Hanson at (xxx) _____.

I would like to
☐ Host home visits
☐ Talk one-to-one with students
☐ Share my family's story with students at USUHS
☐ Participate in discussion groups to plan new teaching and evaluation for medical students

Name: _____
Phone: _____ E-mail: _____

Brochure


Who We Are

We are a group of families, patients, educators and physicians who have identified 203 discrete competencies inherent in the delivery of family-centered care by physicians. The competencies include knowledge, attitudes and skills in the areas of self-awareness, communication, medical decision-making and advocacy. These provide the framework for developing learning goals, teaching strategies and evaluation.


We work with course directors in different departments to develop activities in different courses that are synergistic with goals, address the competencies, and involve parents and patients as teachers.

Department of Pediatrics
Uniformed Services University of the Health Sciences
 Room C-1069
 4301 Jones Bridge Road
 Bethesda, Maryland 20814-2799

Parent staff:
 Sarah Colston, (xxx) _____
 Sue Fisk, (xxx) _____
 Kathy Vestermark, (xxx) _____
 ...plus 114 additional parent faculty and advisors

 **The Family Competency Project**
Uniformed Services University
of the Health Sciences
 (xxx)
funded by a grant from the Josiah Macy, Jr. Foundation

Janice L. Hanson, Ph.D. Virginia F. Randall, M.D., M.P.H.
 jlhanson@usushs.mil vrandall@usushs.mil

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 jlhanson@usushs.mil vrandall@usushs.mil

Home Visits

"It would take pages to tell about all the things I learned visiting this child and his family."
a medical student

Students have opportunities to learn first-hand from a very credible source: families and their children.

Students in a first-year course on the human context of medicine visit families whose children have special needs to talk about helpful doctor/patient/family relationships and issues of uncertainty in medicine.

In the third-year pediatric clerkship, two group discussions augment a home visit that focuses on resilience factors in children with special needs and their families. The students generate ideas about how physicians and the health care system can promote resilience.

Small-group ethics discussions with parents

At the opening session of the second-year bioethics course, students view a documentary film about a very premature infant's life and death and the thoughts and interactions of the parents and medical staff. Small groups of students then discuss the ethical questions in this and similar situations with trained parents who have faced similar critical medical decisions with their own children.

"If this course teaches these young doctors to view a patient as a human being first and a diagnosis second, it will be a success." a parent

New curriculum activities

Over the next two years, we plan to work with other departments and course directors at the university to identify additional areas in which competencies for family-centered care and course goals can be achieved in collaborative activity. We also will convene focus groups of adults with chronic conditions and explore their perspectives on family-centered care, the competencies, and strategies for teaching. We will continue our successful approach of involving parents, patients and families as co-researchers and teachers.

 **Additional activities will be integrated throughout**

Project newsletter

CBILS, Pediatric Interview & Developmental Disabilities Sessions

There are two types of Case-based Interactive Learning Sessions (CBILS), the pediatric interview and the developmental interview. Each one provides third-year medical students with an opportunity to meet real parents and talk about their children in a supportive educational setting, rather than a clinical setting.

The pediatric interview session deals with scenarios involving acute illnesses, such as children with high fevers, painful sore throats, and the inconsolable child that was up all night crying. The students get the opportunity to con-

duct an interview with a the parent and work on their interviewing technique. In the developmental disabilities discussion, the parents tell the story of their child, from diagnosis, through interventions, to progress. The students have the opportunity to understand more complicated medical issues. They can work on how to best approach these more delicate medical circumstances and provide a level of communication that will foster trust between physician and family.

Students have shared their comments about these sessions. When asked what they liked best about the session,

one student responded, "the parent feed-back." Another shared that it was "a chance to hear the story in a non-clinical setting."

Two parents are needed for each session. They occur every six weeks. The wonderful part of these particular sessions is that children are welcome to attend. They add to the realism of the simulated experience. So, if you've wondered how to get more involved but, childcare was an issue, perhaps this is the event for you. For more information on how to participate, contact Kathy Vestermark at vestermarks@earthlink.net.

Home Visits And You: Reach Out and Touch the Future

"I can't believe what a wonderful visit we just had with that doctor. She seemed to hear everything I said and addressed all of my concerns. I wish more physicians could treat us that way." Have you ever thought this to yourself after a very satisfying medical visit for you or your child? Do you want to be proactive and bring your passing thought into reality? There is a way. It is called the Home Visit Program. You, too, can touch the future by participating.

First, what is a home visit? There are three different types of home visits that you can participate in through the project. The first is a visit with a pair of first-year medical students. These students volunteer to visit your family to talk to you about what helps to build a good physician/patient relationship. What types of characteristics do you find appealing in your healthcare provider? Do you appreciate it when your physician takes the time to ask how things at home are going? These are the types of questions that will help the first-year students formulate their idea of what makes the physi-

cian/patient relationship work.

The second type of home visit is in the third-year medical student's pediatric clerkship rotation. Student volunteers will visit with you in your home. This visit, however, has a slightly different goal. The students are interested in understanding how they, as your future pediatrician, can best provide medical care to your family. One of the best ways for a medical student to appreciate the needs of the patient and family is to see what life is like for those people outside of the clinical setting. This visit provides an opportunity for students to witness how a family with a child with special needs functions and how they, as pediatricians, can provide the best, most efficient and professional care possible for this population.

The remaining type of home visit is in the third-year family medicine clerkship. The medical students in this clerkship are required to visit a family and write a short synopsis of what they gleaned from their visit. This visit focuses on recognizing the resilience of

the family. The students, again, visit in pairs and observe how the family interacts and how they access resources, both in the medical arena and the community. They are also interested in how these resources make a difference in the family's life.

It is an amazing experience to share your story and your family with the medical students. They will take the memory of their visit with your family into their future career as a medical professional. You can touch the future in such a simple way. Contact Roberta Harris at 410-721-8171 for more details on how to get involved.



"Students learn about the whole person, the whole family, when they come to visit."



Collaborative Medical Education Project Bulletin

Volume 1, Issue 4 editor: Kathy Vestermark Fall 2004

Helping Meet Healthcare Needs—mCARE

Again and again, patients and families have provided useful and informative insights based on their experience. What better way to develop a needs assessment for children with life-limiting illnesses than to gain insights from their parents and parents who have lost a child as a result of illness?

The plan is to gather families to identify what their needs are for healthcare and community resources. Then, this same group will look at the TRICARE benefit program and how it addresses and meets these needs. Participants will help write recommendations about how to improve TRICARE for

these children and their families.

USUHS is one of four partners involved in this project. Children's Hospice International and the Coordinating Center in Millersville, MD are also partners. Dr. Cheryl Naulty at Walter Reed Army Medical Center directs the entire project.

Dr. Jan Hanson is the principal investigator at USUHS for the needs assessment portion of mCARE (military Children At Risk—Enhancing quality of life). Dr. Ginny Randall, and research associate Mel Bellin are collaborative partners, helping plan and facilitate focus groups and interviews.

In the near future, families in the National Capital Area will be invited to share their experiences as part of an advisory group. Look for details in future Bulletins about this important chance to help develop recommendations that will enhance the quality of life for all children with life-limiting illnesses within the military medical system.



Meet the Staff

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USUHS & Collaborative, Competency-based Medical Education

The Uniformed Services University of the Health Sciences (USUHS) was established in 1972 by Congress. It is the only federal medical school and graduate school of nursing. Operated by the Department of Defense, USUHS pursues a mission that includes teaching, training and research. Graduates of USUHS serve worldwide in the U. S. uniformed services.

The Collaborative Competency-based Medical Education Project is based at the Department of Pediatrics at USUHS. The project involves parents of children with special needs and adults with disabilities and chronic medical conditions as advisors and teachers in the medical education program at USUHS, with funding from the Health Resources Services Administration, U. S. Department of Health and Human Services.

The views expressed are those of the authors and are not necessarily those of the Uniformed Services University or the Department of Defense.

ADVISOR ORIENTATION MATERIALS

Introductory letter for parents

Dear Parents,

The Department of Family Medicine in conjunction with the Department of Pediatrics and the Josiah Macy, Jr. Foundation Project are adding a component to the required third-year medical school clerkship in Family Medicine. This component will have students visit the homes of families with children with special needs to get to know the children, their special needs and how the family has responded to those needs. The students would also work with you to spend some direct time in interaction with your child. The objectives of this educational endeavor are to expose the students to families in their homes, allow them to see firsthand the accommodations made for children with special needs, and then allow them to experience first-hand the joys and frustrations of providing direct care for these children. This will give the students a chance to see the strategies for resilience you have developed to adjust to your special situation. We are extremely grateful for your willingness to share your experiences with future physicians and add an important element to medical education, one that has previously been neglected, resulting in a lack of understanding early in physicians' careers.

Students will visit your homes at a mutually convenient time to talk with you and, possibly, your child and to learn what special things your child requires. We would like the students to spend some quality time interacting with your child in an activity of your choosing. If it works for your situation, the students would also like to offer you the opportunity to go out for a short period of time while they stay with your child or children. The students will always be in at least pairs and rarely groups of three. They will be asking things like your family history and the child's medical history and how your child's condition affects your family. They will also ask questions about the resources that your child needs at home, at school, or in your community, to help them learn about resources for which they can advocate as physicians. If you have any questions about the visit, please call or e-mail Penny Veerhoff at (xxx)_____; pveerhoff@usuhs.mil.

The students will report to attending physicians in both Family Medicine and Pediatrics on their findings but the information will be treated with the same confidentiality as a medical record. If at any time you become uncomfortable with the process you can stop and ask the students to leave. All the students will be in their third-year of medical school with lots of book knowledge but developing interviewing skills and clinical knowledge. They are not visiting to provide medical advice or care, but to develop comfort in dealing with special needs families and making home visits.

We cannot thank you enough for opening your homes and lives to help advance the education of future physicians. Your contributions will have a profound effect on their understanding and ability to help exceptional children and their families.

William S. Sykora, MD
Col, USAF, MC
Undergraduate Coordinator
Department of Family Medicine

3. Appendix

ADVISOR ORIENTATION MATERIALS

Summary of teaching and advising activities

*Collaborative Medical Education Project
Uniformed Services University of the Health Sciences
Janice L. Hanson, Ph.D., Principal Investigator
(xxx) _____*

*Collaborative Teaching Opportunities—
Sharing Patient and Family Perspectives with Medical Students*

- ❖ *Case-Based Interactive Learning Sessions (CBILS)*—Parents participate in interviews and provide feedback to students, or talk with students about their children's development and resources they have needed to support their development.
- ❖ *Advocacy Teaching Sessions*—People who have experienced complex medical needs that require access to a variety of resources talk with students in small groups about ways physicians can understand and advocate for patients and families.
- ❖ *Bioethics Course*—Parents whose children have faced very serious medical challenges as infants or very young children talk with students in small groups, sharing their stories and answering questions about some of their difficult decisions.
- ❖ *Home Visits*—People who have experienced a lot of health care, either for themselves as adults or with their children, invite students to their homes to talk about their experiences and see life outside the clinic and hospital.

*Advising Opportunities—
Sharing Ideas for Medical Education*

- ❖ *Focus groups*—Small groups of people who have had health care experiences gather with one or more faculty facilitators to share their perspectives on a particular topic related to professionalism or communication with physicians.
- ❖ *Written surveys*—Surveys gather written responses to questions about professionalism or communication with physicians, using paper or e-mail surveys.
- ❖ *Interviews*—A faculty member, student, or research assistant asks questions about professionalism or communication with physicians, one-to-one either in person or over the phone.

Introduction to home visits for adults

One-on-One Program

Welcome to the *One-on-One* program. *One-on-One* provides an opportunity for medical students to meet informally with patients who have had multiple medical experiences because of chronic or serious medical conditions or disabilities.

One-on-One enables students:

- to get to know patients in a non-medical setting;
- to learn about living with chronic or serious illness;
- to learn about living with a disability;
- to ask difficult questions in a safe environment; and,
- to explore patients' perspectives on the health care system and the physician/patient relationship.

The Meeting

One-on-One visits can take place in the patient's home, at a mutually convenient location such as a park or restaurant, or on the USUHS campus. The intent of the meeting is informality and comfort, so choose a place where the atmosphere is relaxed and conducive to conversation.

This is not a clinical visit, so there's no need for the student to take notes. The purpose is for the student to get to know the patient. The focus is on building a relationship and listening to the life experiences and observations of the patient. Of course, the confidentiality of the physician/patient relationship applies to this visit.

Topics to Explore

The *One-on-One* program provides an opportunity to explore issues with patients that may not be covered during a typical clinical visit. It provides an opportunity to find out about a patient as a person, as well as about his or her experiences living with a chronic condition. The visit provides an opportunity for you to talk about the physician attitudes and behaviors you have found to be most effective and supportive.

After the One-on-One Visit

We hope students will take the time to reflect on this experience, then write a brief paper summarizing the visit. The paper may highlight two or three things that the student learned that have changed or expanded his or her thinking about physician/patient relationships. The faculty will also plan a time to get together to discuss the visits with a small group of students.

If you have questions, or need additional information please call Jan Hanson (xxx-____), Ginny Randall (xxx-____).

ADVISOR ORIENTATION MATERIALS

Summary of first-year home visit (for parents)

First-year Home Visits

- ❖ *One student will visit.*
- ❖ *The student should come with questions to discuss with you.*
- ❖ *You have the opportunity to tell the student about your family's experiences with illness or disability, doctors, attitudes you have encountered, uncertainty, grief, adjustment to the unexpected and how doctors can help families who face these issues.*
- ❖ *If your child is present (which isn't necessary), please introduce the student to your child and give them some time to get acquainted.*

Summary of pediatric home visit (for parents)

Pediatric (Third-Year) Home Visits

- ❖ *One student will visit.*
- ❖ *Parents choose an activity in which the student can participate with their child.*
- ❖ *The student observes the strengths of your child and family and thinks about how doctors can promote resilience for children and families.*
- ❖ *You have the opportunity to tell the student about doctors who have helped your child and family cope with challenges and how you think doctors can help children and families to be resilient.*

Summary of family medicine home visit (for parents)

Family Medicine (Third-Year) Home Visits

- ❖ *Students visit in twos or threes.*
- ❖ *Students ask about your child's history, your family history, and your child's needs.*
- ❖ *You have the opportunity to tell the students about the resources your child needs at home, at school and in the community.*
- ❖ *You choose an activity for the students to do with your child. You may do something else during this time.*

3. *Appendix*

ADVISOR ORIENTATION MATERIALS

Instructions for veteran advisors who orient new patient- and family-advisors

Orientations for home visits and project participation

Process for Orientations:

First call: Introduce yourself and mention that you work with Dr. Randall and Dr. Hanson at USUHS on the Family Competency Project. Give a brief summary about the purpose of the project (it is on the consent forms). Note your name and date on database form in box at bottom left: "Parent Coordinator Call" and "Parent Coordinator Call Date."

1. Schedule about an hour visit with a new family.
2. Take 2 folders, one to leave with the family and one to refer to while you talk with the family. Each folder should include the following:
 - 2 copies of the consent form
 - A blank database sheet
 - A resilience book
 - Welcome to Holland
 - The Doctor Makes House Calls
 - A packet with explanations of home visits for family medicine, pediatrics, and first-year students
3. Go through the folder with the parents
 - Explain home visits, including a brief explanation of the three different kinds of visits.
 - Explain the consent forms.
 - Explain confidentiality.
 - Explain security of the database (i.e. students and faculty beyond Ginny and Jan do not have access).
 - Ask the parent(s) to sign the consent forms, initial them, and check the advisory activities in which they might be interested. Please check for all three of these to be completed.
 - Leave a copy of the consent form with the parent(s).
 - Ask the parent(s) to share some information for the database form. Record the information as they talk.
 - Answer any questions the parent(s) may have.
4. After the orientation
 - Treat consent forms and database forms as confidential information.
 - Return the signed copy of the consent form to Jan.
 - Return the completed database form to Jan, who will make sure the information is added to the database.
 - Penny will update the database on the zip disk and supply updated versions to Ginny and Jan for their computers. Zip disk will be kept in a locked file drawer.

Scheduling home visits:

- Roberta will schedule all home visits.
- E-mail names for family medicine visits to Bill Sykora (wsykora@usuhs.mil) with back-up copies to Ginny and Jan. E-mail names for first-year and pediatric visits to Ginny and Jan, so they will both have the information in case a student contacts them.

Contact information:

Jan Hanson
(xxx) _____ office
(xxx) _____ home
jhanson@usuhs.mil

JOB DESCRIPTIONS

Home visit coordinator

Home Visit Coordinator

Contract position available

Background: The home visit coordinator provides services for the medical student home visit program at the Uniformed Services University of the Health Sciences. Medical students visit the homes of children with special health care needs or disabilities or adults with chronic medical conditions and complete related assignments as part of their medical school education. Students may elect to participate in their 1st year of medical school and in their pediatric clerkship in the 3rd year of medical school. All students are required to participate in their 3rd year family practice clerkship session in the National Capitol Area.

Qualifications: The home visit coordinator must possess excellent communication and listening skills, both on the telephone and in person. S/he must have experience accessing health care for family members with special health care needs or for his/her own health condition. Experience in helping with teaching of medical education activities and participating in focus groups is desirable. The contractor must complete a Human Subjects Research Protection course within the first month of work. The home visit coordinator must agree to keep information about children, families and adults in confidence and to keep the written database of patients and families in a secure location.

The home visit coordinator is responsible for performing the following tasks:

- Contact parents and adults in the database by phone to schedule them as host families for the 1st year medical students and 3rd year pediatric clerkship medical students in pediatrics. Match students to their geographic or medical condition preference whenever possible. Forward the list of host families to project staff within one week of receiving the names of the students.
 - Approximately 40 host families per academic year for 1st year students.
 - Approximately 6 host families every 6 weeks for 3rd year pediatric clerkship students.
- Provide a list of 15 host families every 6 weeks to the family practice clerkship director on the first day of the clerkship rotation. Ensure these families are able and willing to host 2 family practice students during the first week of each family practice rotation.
- Ensure each host family understands the timeframe for their visit, who will be coming, and what the purpose of the visit is.
 - 1st year students' purpose is to discuss general questions about physician-patient communication and relationships.
 - 3rd year pediatric students' purpose is to learn more about the child's illness and the strategies the family has developed to assist their child to be resilient.
 - 3rd year family practice students' purpose is to learn about the medical and community resources that the family is using and how those resources were obtained.
- Call new host families after their first home visit to discuss the events of the visit and answer any questions.
- When requested by the project staff, assist in recruiting new families as home visit hosts.
- Notify the office staff when new information about a host family becomes available or when information such as phone number or address changes.
- Participate in in-home orientations of new home visit hosts as time in the contract

Information specialist

Information Specialist

Contract position available

The information specialist provides services for the Family Competency Project at the Uniformed Services University of the Health Sciences. This project involves patients and parents in writing competencies for medical education, developing activities to teach those competencies, and implementing the activities across the medical school curriculum. The information specialist position involves 20 hours per week of work for a period of three months, to be performed at the Uniformed Services University of the Health Sciences.

The contractor is responsible for performing the following tasks:

- Organizing information about project participants from three versions of a database into one updated version, and supplying the updated version in a Microsoft Access file.
- Collecting and organizing paperwork about project participants, including a paper copy of the database and consent forms.
- Organizing project files.
- Typing project reports and papers in Microsoft Word.
- Producing mailing labels and preparing materials for mailing.
- Producing notebooks for use in medical student instruction.
- Locating articles in the library and providing copies to project faculty.
- Obtaining copies of newsletters, forms, notifications, and letters and mailing them to project participants.
- Coordinating timing of activities with project faculty.

Patient and family coordinator

Patient and Family Coordinator

Contract position available

The patient and family coordinator provides services for the Family Competency Project at the Uniformed Services University of the Health Sciences. This project involves patients and parents in writing competencies for medical education, developing activities to teach those competencies, and implementing the activities across the medical school curriculum. The coordinator position involves 8 hours per week of work, which can be completed on a flexible schedule from home.

The contractor is responsible for performing the following tasks:

- Scheduling patients and/or parents to participate in focus groups for research and in medical school teaching.
- Participating in recruitment of adult patients and parents of children with special needs to participate in the project, including developing and distributing flyers, writing newspaper notices, organizing patient and family names, answering inquiries about the project and making phone calls.
- Contributing to a quarterly newsletter about project activities and other project publications, which may include conducting interviews, drafting or writing articles, editing articles written by patients/parents or project faculty, and providing input about publication design.
- Gathering information from patients and families, and providing information to patients and families, using a database of project participants.
- Interviewing patients and families by phone and providing summary reports.
- Orienting new patients and families to the project by phone and in person.
- Providing questions to include in interviews, focus groups and written surveys.
- Participating in teaching medical students, in activities developed for the project.
- Coordinating with project faculty to assist with mailings to project participants.

3. Appendix

Database templates for information about advisors

Wednesday, February 02, 2005 11:00:0

Parents			Children	
Father	Title	First Name	Last Name	
Mother				
Guardian				
Home Address				
City				
State				
Zip Code				
Service Branch				
Unit and Duty Station				
Home Telephone:				
Mother Work Phone:				
Father Work Phone:				
Cell Phone:				
Fax:				
E-mail:				
Parent/Family Notes:				
<div><div>Project Administration</div><div>Local: <input type="radio"/> Mailings Only: <input type="radio"/></div><div>Source of Referral:</div><div>Coordinator Call (Who?):</div><div>Coordinator Call (Date):</div><div>Orientation Visit (Who?):</div><div>Orientation Date:</div><div>Macy Consent Form Received: <input type="radio"/></div><div>HRSA Consent Form Received: <input type="radio"/></div><div>Appreciation Certificate: <input type="radio"/></div></div>				
<div><div>Children</div><div>First Spec Needs Child</div><div>Other Spec Needs Child</div><div>Name</div><div>Birthdate</div><div>Condition:</div><div>Surgeries</div><div>Educ Program</div><div>Notes</div><div>Siblings/Birthdates:</div><div>Number of Spec Needs Children, this Family:</div><div>Project Participation</div><div>Ethics Course Participation:</div><div>CBILS Pediatric Interview Participation:</div><div>CBILS Pediatric Development Participation:</div><div>Advocacy Participation:</div><div>Home Visit Participation:</div><div>Home Visit Types:</div><div>Home Visit Program Notes:</div><div>Special Project Participation:</div></div>				

Wednesday, February 02, 2005 11:02:0

Title	First Name	Last Name	Spouse's name	
Address			Employer/Profession	
City	State	Zip Code	Service branch	Unit Duty Station
Work Phone	Home Phone	Cell phone	Voice mail	Fax Number
Email	Birthdate	Referred By		
Chronic condition		Notes		
<input type="radio"/> Home visit participation		<input type="radio"/> Tricare eligible		
Home visit notes		Insurance information		
		<input type="checkbox"/> HRSA consent form received		
Special project participation		Project participation notes		
Other information				

APPRECIATION CERTIFICATES

Certificate for advisors

Certificate of Appreciation

This certificate is presented with gratitude to

For your contribution to the Family Competency Project at the Uniformed Services University of the Health Sciences. Your willingness to share your knowledge and wisdom with medical school students will truly make a positive difference in the delivery of health care in the future.



COL Virginia F. Randall, M.D., M.P.H.
Associate Professor of Pediatrics

Janice L. Hanson, Ph.D.
Research Assistant Professor of Pediatrics

Certificate for students

The Family Competency Project

Certificate of Commendation

This certificate of commendation is presented to

for exemplary service above and beyond the call of duty in listening, developing empathy and learning from a family with a child with special needs. Taking advantage of this opportunity foreshadows a medical career marked by exceptional communication with patients and families, which will earn their gratitude and assist in building respectful partnerships with patients and families.

Characteristics we especially appreciated about you:

(signature(s) of family member(s))

CONSENT FORMS

Home visit consent form

Department of Pediatrics

CONSENT FORM

HOME VISITING PROGRAM
"FAMILY COMPETENCY PROJECT"

DESCRIPTION OF ACTIVITY: The purpose of this educational activity is to provide an opportunity for medical students to visit in the homes of children with special needs and their families. The goals are to have the family provide experiences and discussion that assist the student in understanding their strengths, needs, and perspective. The home visit will last approximately two hours and will be scheduled by the student and family at a time convenient to both. The student will not provide medical care or advice.

RISKS: In discussing your child's condition and your family perspectives with the student, you may experience feelings of sadness, unhappiness, anger and/or frustration. You may end the home visit at any time or withdraw from any future home visits at any time if these feelings become unacceptably unpleasant.

BENEFITS: This activity will benefit the medical student by enabling them to appreciate the extent and kind of information that only a family can bring to medical decision-making. There is no direct benefit to the family.

ALTERNATIVES: You may choose not to participate in this activity.

CONFIDENTIALITY: We will protect confidentiality to the fullest extent provided under law. All of your discussion, opinions, and medical information about your child and family will be considered privileged and held in confidence; you will not be identified by name in any group discussion with the students.

RECOURSE IN THE EVENT OF INJURY: The Department of Defense will provide medical care for DoD eligible members (active duty, dependents, and retired military) for physical injury or illness directly resulting from participation in this activity. Such care may not be available to other activity participants, except in the event of an emergency.

PARTICIPATION: Your participation in these home visits is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you may withdraw or discontinue at any time for any reason, without penalty. You may elect not to respond to questions asked of you during your participation.

OTHER PERTINENT INFORMATION: If you desire additional information about this educational activity, or if any problems arise related to this activity with regard to your rights as a participant, or with regard to any related injury, you should contact the activity directors at USUHS: Virginia Randall, MD or Janice Hanson, PhD, Department of Pediatrics, Uniformed Services University of the Health Sciences, 4301 Jones Bridge Road, Bethesda, MD 20814-4700. (xxx) _____.

CONSENT: Your signature on the reverse side of this page indicates that you consent to host home visits from medical students for an approximately two hour period to provide them an opportunity to get to know your family and your special needs child.

SIGNATURES:

PARENT: I certify that I have received a copy of this consent form: _____
(advisor's initials)

Printed name _____

Signature _____

Date _____

HOME VISIT COORDINATOR:

Printed name _____

Signature _____

Date _____

3. Appendix

CONSENT FORMS

Advisor consent form

<p>Department of Pediatrics</p> <p style="text-align: center;">CONSENT FORM</p> <p style="text-align: center;">For Advisors in the "FAMILY COMPETENCY PROJECT"</p> <p>DESCRIPTION OF ACTIVITY: The purpose of this activity is to provide an opportunity for medical students, faculty, and health care providers to learn about the perspective of patients, parents and other family members when a child or adult has a chronic medical condition or other special need. The goals are to have the family provide insight and discussion that help health care providers and students understand the strengths, needs, and perspectives of patients and families in relation to health care. The patients and parents will share their perspectives and insights through focus groups and other small-group discussion formats, written surveys, telephone interviews, and one-on-one conversations. All activities will fall under the supervision of at least one faculty member at USUHS.</p> <p>RISKS: In discussing your own, your child's or your family member's condition and your family perspectives with students, faculty and health care providers, you may experience feelings of sadness, unhappiness, anger and/or frustration. You may choose on a case by case basis whether to participate in any focus group, discussion, interview, conversation or survey. You may end your participation in a group discussion or interview at any time, decide not to complete a survey, or withdraw from any future activities at any time if these feelings become unacceptably unpleasant.</p> <p>BENEFITS: These activities will benefit medical students by enabling them to appreciate the extent and kind of information that only a family can bring to medical decision-making. The activities will provide opportunities for students to develop questions to further their learning as future physicians, and to include parents as a resource for their learning. Faculty members, physicians and other health care providers will also gain new insights about ways to meet the needs of children, adults and families through the health care system. Patients and families who have participated in similar activities in the past have found that they also benefit by developing insight about the DoD health care system, as well as gaining a better understanding of physicians as people and ways to build good relationships with physicians.</p> <p>ALTERNATIVES: You may choose not to participate in this activity.</p> <p>CONFIDENTIALITY: We will protect confidentiality to the fullest extent provided under law. When you share medical information about yourself, your child and your family, it will be considered privileged and held in confidence. You will not be identified by name in reports or presentations about the project activities.</p> <p>RECOURSE IN THE EVENT OF INJURY: The Department of Defense will provide medical care for DoD eligible members (active duty, dependents, and retired military) for physical injury or illness directly resulting from participation in these activities. Such care may not be available to other activity participants, except in the event of an emergency.</p> <p>PARTICIPATION: Your participation in this study project is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you may withdraw or discontinue at any time for any reason, without penalty. You may elect not to respond to questions asked of you during your participation.</p>	<p>OTHER PERTINENT INFORMATION: If you desire additional information about this educational activity, or if any problems arise related to this activity with regard to your rights as a participant, or with regard to any related injury, you should contact the activity directors at USUHS: Virginia Randall, MD or Janice Hanson, PhD, Department of Pediatrics, Uniformed Services University of the Health Sciences, 4301 Jones Bridge Road, Bethesda, MD 20814-4700. (xxx) _____.</p> <p>CONSENT: Your signature on this page indicates that you consent to participate in advisory activities for USUHS as described above. Each specific activity will be offered as an opportunity in which you may choose to participate or decline to participate.</p> <p>SIGNATURES:</p> <p>ADVISOR: I certify that I have received a copy of this consent form: _____ (advisor's initials)</p> <p>Printed name _____</p> <p>Signature _____</p> <p>Date _____</p> <p>USUHS representative:</p> <p>Printed name _____</p> <p>Signature _____</p> <p>Date _____</p> <p>Please check the activities below that interest you.</p> <p>You may contact me for:</p> <p>_____ Attending small group discussions or focus groups</p> <p>_____ Answering written surveys</p> <p>_____ Sharing my ideas on the phone</p> <p>_____ Sharing my ideas through e-mail</p> <p>_____ Reading drafts of papers or reports and sharing ideas about them</p> <p>_____ Hosting a medical student in my home</p> <p>_____ Speaking to a large group of students</p> <p>_____ Talking with a small group of students</p> <p>_____ Talking with a medical student one-to-one</p> <p>_____ Speaking on a panel</p> <p>_____ Telling my story on videotape</p>
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CONSENT FORMS

Consent form for advisors to participate in research

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Department of Pediatrics

CONSENT FORM

For Advisors in Uniformed Services University Protocol G186FB
"COLLABORATIVE, COMPETENCY-BASED MEDICAL EDUCATION"

INTRODUCTION

You are being asked to participate as an "advisor" in a research study designed to develop better methods to teach and evaluate medical students. You have been asked to participate in this study because you are the parent of a child who has experienced repeated encounters with the medical system, or you or a close family member has been a patient who has experienced repeated encounters with the medical system. By telling us about your experience, you can help us understand how physicians and other health care providers can better meet the needs of patients and families. The study and your participation will take place over a period of 2 ½ years, from May 2003 through October 2005.

PURPOSE AND PROCEDURES

This study will involve parents, patients and family members who have had repeated encounters with the medical system in developing new ways to teach and evaluate the communication and professional behavior of medical students. These parent and patient advisors will attend meetings, participate in interviews, host students in their homes, review written materials, and share their experiences with students at the medical school. An advisor may participate in one or more activities during the three years of the project, from May 2003 through October 2005. Faculty, research assistants or medical students will participate in focus groups, interviews and meetings, and will review the information shared by advisors. Publications and presentations based on the information you provide will be presented at scientific and medical education conferences and in the open science and lay literature.

DESCRIPTION OF STUDY

Advisors may participate in the study in several ways. You are invited to volunteer to participate in the following kinds of events:

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A. Focus groups, interviews and written surveys: Focus groups, interviews and written surveys will ask for suggestions for teaching activities and evaluation tools that will be developed for USUHS medical students. We may ask you what topics are important to teach new doctors, what skills and abilities you think doctors need, and what ideas you have about ways to teach these skills and abilities. Focus groups will happen at USUHS. Parent and patient advisors will participate in the focus groups; USUHS faculty members, research staff, and medical students will ask questions at these groups. Interviews and written surveys may be done at USUHS, over the phone, or in your home.

B. Family Visits: Medical students may come to your home to meet you, your child, and/or your family, to learn about your medical needs and your life at home and in the community. These visits will last approximately one to two hours. Medical students who visit your home will learn about your medical information, but will treat it confidentially.

C. Co-Teaching: Parent and patient advisors will also be invited to speak to and participate in discussions with students at USUHS, as part of the students' learning about pediatrics and family medicine.

F. Reviewing written materials: When the faculty and research staff of the study write teaching plans, evaluation tools, or reports about the study, parent and patient advisors will read these materials and offer suggestions for editing them.

G. Collaborative planning meetings: Faculty and research staff working on the study will hold planning meetings for the project, and parent and patient advisors will be invited to participate in these meetings to help plan ways to teach and evaluate medical students.

POSSIBLE RISKS OR DISCOMFORTS FROM BEING IN THIS STUDY

There are no anticipated individual health or injury risks associated with this study. There are no anticipated risks to psychological health. You may experience feelings of sadness, unhappiness, anger and/or frustration as a result of discussing your child's or your family member's condition and your family's perspectives on your health care experience. You are free to decline to answer any questions. You are also free to stop participating in the study at any time.

If you have been feeling generally worse than you normally do, you may wish to contact a health care provider in your area. If you are active duty military, contact your primary care manager, call 1-888-999-5195 or visit www.tricareonline.com to make a primary care or mental health appointment through TRICARE. Otherwise, consult your regular doctor or refer to listings under "physicians" in your local phone book, and ask for a referral to a mental health professional. You may also contact the American Psychological Association for a referral to a psychologist in your area by calling 1-800-964-2000. The operator will use your zip code to locate and connect you with the referral system in your area.

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3. Appendix

CONSENT FORMS

Consent form for advisors to participate in research (cont'd)

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BENEFITS

Your participation will not benefit you or your family members, but may help to develop better methods to educate medical students and evaluate their professional competence.

ALTERNATIVES

You may choose not to participate in this study.

AMOUNT OF TIME FOR YOU TO COMPLETE THIS STUDY

The study will run for a period of two and one half years, from May 2003 to October 2005. Depending on the study event in which you choose to participate, the time you invest could range from no time to 8 hours during a given month. The amount of time required for particular events will vary. Focus group sessions are scheduled for two hours per session. Individual interviews in person or via the phone may take up to 45-60 minutes. Visits of medical students to your home may take up to 2 hours per visit. Your participation via email may take up to 30 to 60 minutes of your time each month. Collaborative planning meetings will take 1 to 2 hours. Co-teaching sessions will take 1 to 3 hours. It may take 30 minutes to an hour to review a written report, teaching plan or evaluation tool.

APPROXIMATE NUMBER OF PEOPLE TAKING PART IN THIS STUDY

There will be approximately 150 advisors participating in the study, composed of up to 100 parent advisors and 50 patient advisors over the three years. Approximately 400 medical students will participate across 2 ½ years.

COMPENSATION

Study advisors who participate in focus groups, co-teaching, or collaborative planning meetings at USUHS will be compensated \$50. Study advisors who participate in interviews or review written materials will be compensated \$30 for each item reviewed. You or your family members will receive no other payment or medical treatment as a part of this study. There is no compensation for hosting a home visit for a medical student.

PRIVACY AND CONFIDENTIALITY

Confidentiality of your and your child's information will be maintained to the fullest extent possible under existing regulations and laws. Your name will not appear in any published paper or presentation related to this study without your express written consent, and then only to acknowledge your contribution to the study. Information that can be linked to you will be stored in locked cabinets in the offices of the Principal Investigator, Dr. Janice Hanson, Ph.D., on the premises of Uniformed Services University in Bethesda, Maryland. Electronic data files with information about you will be password protected and access to these files will be restricted to members of the study staff.

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In addition to the study staff, officials of the Uniformed Services University, and/or other government officials may review files from this study as part of their responsibility to review research records and protect human subjects of research. These duties include making sure that research subjects are protected.

Complete confidentiality cannot be guaranteed, particularly to participants who are military personnel, because information bearing on your health may be required to be reported to appropriate medical or command authorities.

If you participate in an interview and consent to have this interview recorded by audiotape, a GS or contract staff member hired and trained by the project may transcribe the interview. All project staff members who handle data for the project will complete ethics training about research involving people. Transcripts and notes of interviews in which you participate will be kept in unmodified form and will be retained indefinitely as confidential research data. Your social security number will not be associated with these interviews. Tapes used during interviews will be destroyed or erased after the interviews are transcribed.

RECOURSE IN THE EVENT OF INJURY

The Department of Defense (DoD) will provide medical care for DoD eligible members (active duty, dependents, and retired military) for physical injury or illness directly resulting from participation in these activities. Such care may not be available to other activity participants, except in the event of an emergency.

PARTICIPATION

Your participation in this study project is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you may withdraw or discontinue at any time for any reason, without penalty. You may elect not to respond to questions asked of you during your participation. You may choose on a case by case basis whether to participate in any focus group, discussion, interview, conversation or survey. You may end your participation in a group discussion or interview at any time, decide not to complete a survey, or withdraw from any future activities at any time if these feelings become unacceptably unpleasant.

IF YOU HAVE ADDITIONAL QUESTIONS OR CONCERNS

If you desire additional information about this research study, or if any problems arise related to this study with regard to your rights as a participant, or with regard to any related injury, you may contact the Principal Investigator at Uniformed Services University: Janice Hanson, PhD, Department of Pediatrics, Uniformed Services University of the Health Sciences, 4301 Jones Bridge Road, Bethesda, MD 20814-4700. (xxx) _____. If you have any questions about your rights as a participant in this research study, you may also contact the Director, Human Research Protections Programs at the Office of Research, Uniformed Services University, 4301 Jones Bridge Road, Bethesda, MD 20814, Phone (xxx) _____. If you believe the government or one of the government's employees has injured you, a claim for damages (money) against the federal government (including the military) may be filed under the Federal Torts Claims Act. Information about administrative or judicial avenues of compensation is available from the University's General Counsel at (xxx) _____.

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CONSENT FORMS

Consent form for advisors to participate in research (cont'd)

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CONSENT: Your signature on this page indicates that you consent to participate in this research study as described above. Each specific activity will be offered as an opportunity in which you may choose to participate or decline to participate.

Please check the activities below that interest you at this time. Your selections today do not commit you to participate in these activities. You may change your mind at any time.

I am interested in:

<input type="checkbox"/> 1. Hosting a medical student in my home	<input type="checkbox"/> 6. Reading drafts of papers or reports and sharing ideas about them
<input type="checkbox"/> 2. Speaking to a large group of students	<input type="checkbox"/> 7. Speaking on a panel
<input type="checkbox"/> 3. Talking with a small group of students	<input type="checkbox"/> 8. Talking with a medical student one-to-one
<input type="checkbox"/> 4. Sharing my ideas through e-mail	<input type="checkbox"/> 9. Telling my story on videotape
<input type="checkbox"/> 5. Answering written surveys	<input type="checkbox"/> 10. Sharing my ideas on the phone

SIGNATURES

ADVISOR: I certify that I have received a copy of this consent form: _____
(advisor's initials)

Printed name _____

Signature _____

Date _____

UNIFORMED SERVICES UNIVERSITY REPRESENTATIVE:

Printed name _____

Signature _____

Date _____

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I certify that the research study has been explained to the above individual, by me or my research staff, and that the individual understands the nature and purpose, the possible risks and benefits associated with taking part in this research study. All questions that have been raised have been answered.

PRINCIPAL INVESTIGATOR: _____

DATE: _____

G186FB v 4 June 2004 Subject Initials _____ Date _____ Witness Initials _____ Date _____